

**Alzheimer's State Plan Task Force
DRAFT Meeting Minutes
Monday, November 16, 2009**

Attendees:

Lt. Governor Peter Kinder	Dr. John Morris, Washington University
DHSS Dir. Margaret Donnelly	Joe Palm, DHSS
DIFP Dir. John Huff	Gwen Richards
Sen. Bill Stouffer	Carroll Rodriguez, Mo. Alzheimer's Assoc.
Julie Ballard, DHSS	Lois Zerrer, J.D.
Lisa Baron, Memory Care	Lynn Carter, DMH
Joan D'Ambrose, St. Louis Alzheimer's Chapter	Glenda Meachum-Cain, DHSS
Dr. Maureen Dempsey	Theresa Valdes, DSS
Deborah Ellis, JCC Adult Day Care	Richard Aubuchon, LTG
Jean Leonatti, CMAA	Patrick Lynn, DHSS
	Jason Echols, Mo. Alzheimer's Assoc.

Tour of Jewish Community Center's Adult Day Services

Welcome from Lt. Governor Peter Kinder and introduction of task force members.

Barry Rosenberg, President of Jewish Federation, welcomed task force and discussed the federation and its programs.

Richard Aubuchon presented on HB 272

- Bill overview can be found at <http://blogs.mo.gov/alztaskforce/2009/11/firstmeeting.html>
- No comments

Carroll Rodriguez presented *Looking at the Past, Planning for the Future*

- PowerPoint can be found at: <http://blogs.mo.gov/alztaskforce/2009/11/looking-at-the-past-planning-for-the-future.html>
- Overview of previous Alzheimer's task force and advancements to date
- Need to update definition of Alzheimer's Disease
- Found training and education of health care professionals to be out-of-date.
- Final report of last task force is online along with other documents
 - Can print on request (Patrick Lynn)
- John Morris Comments:
 - Only 25 years of understanding AD as a clinical diagnosis; MO's first state plan was groundbreaking/trailblazing
 - MO has put into legislation who will make decisional capacity for someone without advanced directives
 - Remember to also focus on rural areas, not just urban
 - Research should be a focus of task force – so that we can ultimately beat AD and not just treat it

Lt. Governor Kinder thanked Dr. Morris for his comments and recognized the advocacy work of Sen. Stouffer in the state senate.

Break (Lt. Governor Kinder and DHSS Director Margaret Donnelly left.)

Discussion

Richard Aubuchon and Patrick Lynn opened the meeting to general discussion on where we go from here.

Lois Zerrer asked about geographical meeting requirements. Mr. Aubuchon answered that those would be for public testimony.

Dr. Morris asked what are we trying to accomplish with the plan in November 2010. Sen. Bill Stouffer said the goal of the legislation was to know where we are and what is needed to move forward.

Lisa Baron added that we need to develop model network on how we communicate and deliver services. This is an opportunity to develop a national model.

Joan D'Ambrose said we should look at what other state task forces did and how they were structured.

Lynn Carter recommended a committee of the whole for public comment and decisions, but then we should be judicious with w/subcommittees.

Richard Aubuchon requested member ideas on committees?

Richard Aubuchon's Committee Ideas:

- Research Update Committee
- Legislative Committee
- Impact Committee
- Existing Service Committee

Jean Leonatti suggests that during 4 geographic meetings – sub-committees will make update reports. Jean's suggested sub-committees:

- Family & Individuals
- Professional Caregivers
- Research
- Current Snapshot – Impact
 - Carroll Rodriguez – Don't need a committee on facts/impact since the data is already there.
 - Can there be staff support to compile information on prevalence, impact, costs, etc.
 - Carroll Rodriguez – since task force has limited resources, Alzheimer's Association staff can do

Carroll Rodriguez adds:

- Medicaid
- HCBS/LTC
- Quality Care

John Huff adds to Jean's:

- Funders & Payers – LTC Insurance

Maureen Dempsey recommended charging committees with specific duties and boundaries

Lois Zerrer recommended a focus on finances and the overall impact on society and the state of the cost of care.

Mr. Aubuchon recommended a Research Committee that would be lead by Dr. Morris and Dr. Dempsey. Dr. Dempsey requested that she also be assigned to quality and regulations. Dr. Morris accepted.

Joe Palm asked how AD was classified in death certificate. Dr. Morris replied that AD is underreported because the immediate cause of death is caused by AD. Dr. Dempsey agreed and expressed a need to educate physicians to be more complete on death certificates. Mr. Palm summed up that this should be a concern for the task force as it affects funding and program targets.

Ms. Ellis stated that Alzheimer's is under reported in life, too. Dr. Morris concurred that around 50% is not recognized. Ms. Richards expressed concern that many individuals who have it are not diagnosed and this leaves their family members uninformed.

Ms. Carter recommended a family support and intervention committee.

Ms. Rodriguez reminded committee that legislation specifies the task force focus on Alzheimer's and Individuals with Down's syndrome. She recommended that the task force set duties for the research committee.

Dr. Morris wants to focus on who is conducting research, what is being researched and what is needed. Dr. Dempsey wants to look at how we use research to inform actions. Ms. Carter added how research informs public policy. Ms. Rodriguez added the need to inform the community about research. Mr. Aubuchon summarized as:

- Snapshot
- How does it shape public policy
- Consumer awareness

Ms. Leonatti recommended a committee on professional care giving system

- Assistance for those handling own care
- Quality of care
- Regulatory needs

Ms. Ellis added that adult day care needed to be included. Ms. Leonatti recommended focusing on licensed and direct services. Dr. Dempsey stressed the need for focusing on the continuum of care and professionals involved. Ms. Leonatti stressed professional not services. Ms. D'Ambrose recommended using HB 603 as guide-training all professionals through each stage. Ms. Leonatti stressed that this committee should focus and continuum of care needs and that another committee could look at what services we don't have, but need.

Ms. Valdes recommended that each committee use gap analysis.

Ms. Baron stressed the need for broad spectrum of public input – rural, wage levels, etc. Ms. Rodriguez mentioned the community forums – many individuals will take part.

Ms Rodriguez recommended one Service Committee with 2 sub-committees: HCBS and Residential. Ms. Carter stressed there needs to be coordination and joint meetings between them.

Ms. Leonatti recommended committees be called “Quality of Care Along the Continuum” and “Services” split into HCB and residential. Ms. Zerrer asked if there are any other services. Ms. Ellis mentioned adult day care. Mr. Aubuchon recommended setting out on the continuum - 1. Home, 2. Community, and 3. Residential. Ms Rodriguez mentioned special needs populations.

Ms. Leonatti recommended a Preparing for AD Committee – what can you do to prevent and prepare for AD and testing. Sen. Stouffer mentioned the need to raise public awareness. Ms. Baron asked if that was a gap and Mr. Aubuchon replied that committees will identify gaps.

Ms. Rodriguez stated that research is focused on prevention, should public health and awareness be part of every committee. Ms. Baron stressed creating deliverables for each committee. Dr. Dempsey mentioned that central to families is how to navigate the system and asked how we shape efforts around that. Mr. Palm mentioned need to educate police and firefighters. Mr. Aubuchon said these are all duties for quality of care committee.

Dr. Dempsey said committee should look at what standards exist. Gaps in professional training and education, public policy and recommendations, and each service provided in continuum. Ms. Richards stressed the need to for communications training for health care professionals on how to interact with patients.

Mr. Aubuchon moved discussion to the services committee. Ms. Leonatti recommended identifying services along the continuum and focusing on gaps in HCB and residential. Ms. Carter recommended the name Service Delivery System.

Mr. Aubuchon summed up the discussion of committees to this point.

Ms. Zerrer stated that she keeps coming back to finance – how do families pay, cost to state.

Mr. Aubuchon opened discussion on need for 4th committee. Ms. Zerrer recommended a Finance committee. Ms. Leonatti stressed the importance of public education – insurance, power of attorney, nutrition and brain activities. Future directions and recommendations need to be part of

final report, but does it warrant another committee? Ms. Carter said issues are so entangled that as a task force – must pull together separate committees to synthesize these issues in a way that future recommendations, preparations, funding, etc. should be part of the final report.

Sen. Stouffer state the need to create a body of knowledge that people can go to and to identify any legislation that needs to happen.

After the task force is dissolved it might be good to put together a model network of involved individuals – how the diverse groups brought together by the task force will continue to work together.

May want to join with conferences on Alz and hold meetings in conjunction with these to access experts.

Final Committees

*Members can also come from outside of task force

- **Research Committee**

- Purpose:
 - Snapshot of AD related research taking place in MO and how the state can support that research.
 - How can current research support the goals of this task force and inform public policy? (Evidence-based practice is a bridge with services committee.)
 - Reaching out to community for awareness of current research. Stakeholders and public awareness.
- Chair(s)
 - Dr. John Morris (Chair)
- Expressed Interest in Being Involved:
 - Dr. Maureen Dempsey

- **Quality of Care Along the Continuum**

- Purpose:
 - Understand and define the continuum. What are the requirements and credentials for professionals?
 - Public policy
 - Professional education
 - Are we prepared for the future?
 - Sensitivity training for doctors/Health Literacy for Community
- Chair(s)
 - Dr. Maureen Dempsey (Chair)
 - Julie Ballard (Co-Chair)
- Expressed Interest in Being Involved:
 - Joan D'Ambrose

- Discussion of scope included paid professionals with hands on care, regulations, quality care, etc.; nursing homes, ALF, Adult Day services, etc., NOT community services; professional education, and Professional credentials
- **Service Delivery System Committee**
 - Three sub-committees within this committee:
 - In-Home Services
 - Community Services
 - Residential Services
 - Purposes:
 - Identify services along continuum
 - Chair(s)
 - Jean Leonatti (Chair)
 - Carroll Rodriguez (Co-Chair)
 - Expressed Interest in Being Involved
 - Gwen Richards
 - Julie Ballard
 - Glenda Meachum-Cain
 - Teresa
 - Lynn Carter
 - Lois Zerrer
- **Deliverables for each committee**
 - Focus on special populations of the bill:
 - Early-stage Alzheimer's
 - Early onset Alzheimer's
 - Individuals with Alzheimer's disease and Down's Syndrome
 - Gap analysis in every committee – what's not there that should be
 - In meetings across state we should be hearing from diverse groups – rural, lower SES, etc – to identify gaps from people going through services
 - Public Awareness
 - Lois: It's more than public awareness – it's about understanding and respecting the rights and dignity of persons with dementia

Future Meetings and Community Forums

- Proposed next date:
 - Columbia, MO
 - Public Forum on January 25 (evening)
 - Community Forum followed by Task Force on Tuesday, January 26
- Must have a minimum of 4 community forums (legislation) – Decided on having 5
 - Will seek public input at community forums in:
 - St. Louis
 - Kansas City
 - Springfield

- Columbia
 - Cape Girardeau
- Reason for original 4 – At the time the bill was written, there are 4 Alzheimer’s Association chapters across the state
 - Alzheimer’s Association chapters can help with the 5 community forums
- Question about meetings in diverse locations – what’s the goal?
 - To make travel for public easier to come to forum
 - Community forums – seeking public input from across the state
 - This meeting does not count as one of the four geographical meetings
- Discussion and Proposals (not decided)
 - Community forum will take place in conjunction with task force meeting
 - Have public forum in morning or evening with task force meeting the next day
 - **Action Item** – Carroll will email out model of community forums
 - Public input done early and should drive subcommittees – done by July?